

## ABSTRACT

### SOCIAL WORK

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A DESCRIPTIVE STUDY OF THE RELATIONSHIP BETWEEN SOCIAL  
SUPPORT AND THE QUALITY OF LIFE AMONG HIV-POSITIVE  
AFRICAN-AMERICAN WOMEN

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Human immunodeficiency virus (HIV) has significantly infected and affected African-American women and their families. HIV has significantly impacted the social support system and the quality of life of women who are infected.

In an effort to measure the importance of social support on the quality of life among African-American women, a social support questionnaire and quality of life survey was administered to 28 African-American women in Oakland, California who are HIV-positive or had an AIDS diagnosis.

The results of this study demonstrated that substitute support systems are created when family support systems have diminished or no longer available. The participants in this study affirmed that a woman's quality of life is an individual's concept based on her established relationships with the people and agencies of her support system.

A DESCRIPTIVE STUDY OF THE RELATIONSHIP BETWEEN SOCIAL  
SUPPORT AND THE QUALITY OF LIFE AMONG HIV-POSITIVE  
AFRICAN-AMERICAN WOMEN

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BY

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## CHAPTER I

### INTRODUCTION

Twenty years ago, an unknown epidemic was prevalent in the gay, white male community. In 1983 the virus that triggered the epidemic was renamed from Gay Related Immune Deficiency (GRID) to Acquired Immunodeficiency Syndrome or AIDS. The renaming occurred as the disease became more noticeable in women, children, and families.

Upon the emergence of AIDS, the African-American community paid little attention to the epidemic, believing that the disease only affected the gay, white male population and the individuals that resided in Africa and Haiti. Reaction from the community's leadership was slow and religious leaders used the disease to condemn promiscuous lifestyles as well as homosexuality. As time and the epidemic progressed, women, children, older individuals and various members of minority groups began to appear in AIDS statistics tracked by the Center for Disease Control ([www.avert.org](http://www.avert.org)).

In the United States, the human immunodeficiency virus (HIV), which is the virus that causes AIDS, has spread into every sector of the African-American community. The impact of HIV and AIDS on this community was corroborated during the May 1998 meeting of the Congressional Black Caucus (Waters, 1999). During the meeting, an

appeal was made to the Department of Health and Human Services (HHS) to declare AIDS in the African-American community a federal state of emergency (Waters, 1999). African Americans composed 12 percent of the nation's population yet accounted for 61% of the AIDS cases that have been documented since the Center of Disease Control began to record the disease progression in 1981 ([www.avert.org](http://www.avert.org)). In 2003, African-American and Hispanic women comprised more than 83% of HIV/AIDS cases among women in the United States although this group represented only 25% of all women in the United States ([www.cdc.gov](http://www.cdc.gov)). Statistics from the Center for Disease Control indicated that in 2001, AIDS was one of the four leading causes of death in African-American women in the 18-44 years old childbearing age group and the 6<sup>th</sup> leading cause for all women aged 25-34 ([www.cdc.gov](http://www.cdc.gov)).

Responses to the spread of AIDS among African-American women should address the particular experiences and needs of that population in a manner that is culturally competent. Despite the speed in which AIDS has become prevalent in the lives of African-American women, the research on the factors that have contributed to the dilemma and on best practices for intervention has been slow to occur. Upon diagnosis, the HIV-positive woman is faced with decisions that affect her everyday life and health. HIV-positive African-American women are often forced to continue functioning regardless of their health status due to several reasons. Reasons can include her role in the family, community, social and economic status and her failure to receive adequate care once diagnosed (Aranda-Naranjo & Davis, 2000).

These women do not have the luxury of relinquishing the daily roles and responsibilities of spouse, mother, provider and caregiver. Many of these women live in poverty and are single mothers with dependent children (Owens, 2003). Their health is often secondary to that of their children so medical services are sought in the latent stages of HIV. This responsibility coupled with poverty and culture is why some women are denied the opportunity to live with HIV and often die from AIDS (Tolliver, 2001). There is a need for intervention from family, friends and community to assist a woman in improving her health as well as her quality of life.

#### Background of the Problem

Between the years of 1978 and 1981, the first reported cases of GRID were documented. The disease was the source of deaths for gay males, and heterosexuals from Tanzania and Haiti (Olufs, 2001). By the end of 1981, there were 422 documented cases of AIDS. Five of the reported cases are women.

The progression of GRID-related deaths from the gay males community to other populations occurred and GRID was redefined as AIDS in 1982. The representation of women was noted in CDC reports. The majority of the cases identified HIV-positive women as having a history of substance abuse and prostitution (Olufs, 2001). During this time, grassroot support organizations began to appear within the white gay and lesbian community. Lesbians and heterosexual women were finding themselves taking care of their gay male friends who were quickly dying from this disease. Structured HIV women specific support groups and services would not occur until 1987.

In 1983, the CDC warned the public that blood from blood banks were infected with an unknown virus, later identified as HIV. Women were infected through blood transfusion. Women from various backgrounds and age groups were integrated in documented cases. Documented cases of AIDS within the United States grew to 4,749 with 2,122 reported deaths (Olufs, 2001).

By 1987, the number of documented AIDS cases in the United States was 71,176 with 41,027 reported deaths. Women represented more than seven percent of the reported AIDS cases in the United States. That year the CDC allocated funds from state and local health departments for HIV/AIDS services that focused on African Americans and other minorities (Olufs, 2001). Support services agencies that focused on women opened their doors and delivered women-specific services. During 1987, Glaxo Wellcome introduced the first anti-HIV drug, zidovudine/azidothymidine (AZT) (Olufs, 2001). Women were omitted from the drug trials of the anti-HIV drug because they are unable to meet the entry requirements of the trials and most AIDS cases among women were misdiagnosed/undiagnosed by clinicians (Kurth, 1993). By 1988, women were among the fastest growing population with HIV diagnoses (Wilder, 2002).

During 1989 to 1990, support service organizations for women emerged and targeted the African-American community. The organizations focused on the needs of women infected and affected by HIV/AIDS. In 1990, the CDC reported that 70 percent of AIDS victims were heterosexual African-American and Latino males. Seventy percent of the reported AIDS cases among women and seventy-five percent of pediatric AIDS



cases were members of these two ethnic groups (Hutchinson, 1992). The sources of infection were traced to gay male sexual behaviors, male-to-female sexual contact, infected blood through transfusion (between 1977-1985 before the testing of blood) and intravenous drug use.

With the announcement of his HIV positive status in 1991, Ervin “Magic” Johnson, an African-American professional basketball player, changed the face of HIV. His revelation awakened, confused, and challenged the African-American community’s beliefs about the virus ([www.aegis.org](http://www.aegis.org)). The disease no longer just represented the stereotypical gay, white male, substance abuser, prostitute, Haitians and African immigrants. The African-American community now saw the new face of HIV, which represented the heterosexual, married, and non-substance user African-American male.

By 1996, AIDS was the leading cause of death among African-Americans aged 25-44. 548,102 AIDS cases had been documented in the United States and 343,000 people were dead including African-American tennis great, Arthur Ashe and rap star Eric “Easy-E” Wright (Olufs, 2001). National African-American leaders convened at Harvard Institute to raise AIDS awareness among African Americans. The group addressed the reported decline of AIDS within the white community and the steady increase of AIDS cases among African Americans. The leaders discussed barriers that excluded African Americans from receiving medical services, prevention and educational services that were culturally sensitive to this ethnic group ([www.thebody.com](http://www.thebody.com)).

The CDC reported, in 1998, that 63% of the newly reported AIDS cases were

African-American women and these women were three times more likely to die from AIDS than any other United States female ethnic group (Olufs, 2001). Key members of the women health and HIV community assembled together and advocated the need for HIV prevention options for women which included ensuring minority women were aware and participated in drug trials (Kurth, 1993).

In 1999, small groups of leading African-American advocates assembled in Atlanta for a meeting sponsored by the CDC. The purpose of the meeting was to discuss HIV outreach efforts specifically for the African-American community. African-American religious leaders were asked to present a call to action to their congregation and communities ([www.thebody.com](http://www.thebody.com)). Issues of substance abuse, education, homelessness, unemployment and teenage pregnancy were included in the discussion about African-American women and their rising rate of HIV transmission in comparison to non-minority groups. The need for a call to action that addressed the needs of African-American women was pushed to the forefront and the African-American faith-based community was forced to notice.

The latest figures that have been compiled by the National Institute of Allergy and Infectious Disease through July of 2004, reported that "...more than 20 million people with HIV/AIDS have died since the first AIDS cases were identified in 1981." ([www.niaid.nih.gov](http://www.niaid.nih.gov)). Records from the CDC during that same time period indicated that women living with AIDS has continued to increase while the number for men living with AIDS has decreased. African-American and Hispanic women continued to represent

83% of AIDS diagnoses reported in 2003 ([www.cdc.gov](http://www.cdc.gov)). The infection rates for women were 75% heterosexual contact and 25% injection drug use ([www.naid.nih.gov](http://www.naid.nih.gov)). The CDC also recorded that from the time period of 1990 to 2001, the number of AIDS cases in adults age 50 and older quintupled. This increase was due to the introduction of Viagra, the male sexual stimulant and the HIV drug therapy (cocktail) that has allowed people infected with HIV/AIDS to live longer ([www.thebody.com](http://www.thebody.com), July 2003).

As the disease has progressed and has been characterized as a manageable disease, federal funding for social service agencies has been reallocated to other health issues. The shifting of funds has caused many agencies to cease providing services to their clientele. The agencies that continue to operate have incorporated more prevention and intervention services that address the needs of the affected families and communities.

#### Statement of the Problem

African-American women continue to be one of the largest populations infected and impacted by HIV. The formal and informal support systems of HIV-positive women should collaborate to provide the emotional, informational and tangible supports that are needed for them to survive. The barriers that occur in a woman's social support network directly impact her quality of life.

#### Purpose of the Study

The purpose of this study is to examine social support and the impact it has on the quality of life of HIV-positive African-American women. Family, spiritual, and community support systems will be examined as well as barriers that can occur within

these support systems. The nature of the paper indicates the use of available resources in a woman's social support network to improve her quality of life.

### Significance of the Study

The significance of this study is four-part. The first is that HIV/AIDS continues to have the hardest impact on the African-American community 20 years since it's discovery. African-American women continue to represent the growing number of those who are infected. Secondly, the study might be of importance to service providers to increase the planning and implementation of HIV prevention and intervention services that are culturally sensitive and specially target African-American women.

The third part is, HIV/AIDS has traumatized the African-American family and information might be given about efforts that might be made by an HIV-positive woman's informal and formal support network to keep the family intact. When the family becomes fragmented, children are placed in the foster care system or with relatives (kinship care) who may not welcome them. The foster care system becomes overwhelmed with children who have seen the devastation of the disease and who are likely to endure the stigma associated with HIV/AIDS.

Lastly, this study might be relevant to social work practice in that HIV/AIDS shows no sign of decreasing in the African-American community. The possibility of a social worker working with a woman infected or affected by HIV is inevitable. HIV/AIDS is a challenge to all social workers and they should become familiar with agencies that provide services and relevant information to HIV-positive African American women, their partners and/or families. Additional services should be designed

that are gender specific, appropriate for her role as head of household and primary caregiver of her minor children. In conclusion, culturally sensitive, gender-specific health and social services are imperative to addressing the needs of HIV-positive African-American women.

## CHAPTER II

### REVIEW OF THE LITERATURE

The purpose of this literature review was to examine social support as it relates to HIV-positive African-American women and the quality of their lives. This chapter provides: (a) a synopsis of the history of HIV and African American women as it relates to the risks and psycho-social factors, (b) state interpretations of the various types of social support (family, spiritual and community) and distinguish the difference between formal and informal support systems (tangible, emotional and informational), (c) discuss barriers to social support, and (d) explain the quality of life as it pertains to women infected with HIV.

#### History of African-American Women and HIV

Throughout the history of HIV/AIDS, the role of women has been portrayed as twofold: (a) women as the transmitters of HIV to men and children and (b) women as the caretakers, protectors and informational center for people living with HIV/AIDS (Squires, 1993). No full-scale analysis of women and AIDS was incorporated into CDC reports until the middle to late 1980s even though the first cases of AIDS among men appeared in 1981 (Squires, p. 165). Primary modes of transmission were identified as exchange of blood and vaginal secretion, use of contaminated needles and postpartum

(after birth) perinatal transmission.

Time progressed, the HIV epidemic continued, and the demographics of the infected community changed. An increase was recorded among intravenous drug users, racial and sexual minorities, lower socioeconomic individuals and particularly women (Stuntzner-Gibson, 1991). Most of the women were identified as poor, sex workers, substance abusers and /or women of color (Kurth, 1993, p. 5). In the article, *Women and HIV Disease*, Stuntzner-Gibson (1991) notes, “when women contract HIV, they often are regarded with suspicion and the typical societal response is focused on blaming them for infecting children, when they are mothers, or men when they are prostitutes.”(p. 22-23). Unfortunately this belief was embraced as truth as government officials slowly extricated funding for research, which focused on women and provided accessible health services and social services for communities of color.

### Risk Factors

As the number of HIV cases declined in the gay, white male community, the number of newly identified HIV cases continued to increase for African-American women and men. Heterosexual transmission was identified as one of the major source of HIV transmission within this population (Worthy & Fleming, 1997). Statistics at the 1999 National Conference of African American and AIDS reported that AIDS was the leading cause of death in the 25-44 age category in African-American men since 1990 ([www.cdc.gov](http://www.cdc.gov)). The leading cause of HIV infection for African-American men was and continues to be recorded as men having sex with other men (MSM) followed by injection

of drugs and heterosexual contact ([www.cdc.gov](http://www.cdc.gov)).

Death among African-American women in the same age group was charted since 1993. The leading cause of HIV infection for African-American women was recorded as heterosexual contact followed by injection drug use ([www.cdc.gov](http://www.cdc.gov)). Women in this age range (25-44) were of childbearing age. Reports in 2002, noted that sixty-two percent of HIV-positive children were born to HIV-positive African-American women ([www.niaid.gov](http://www.niaid.gov)). These HIV-positive children were placed with relatives or in the foster care system. The highest increases of AIDS and HIV among women were located in the east and southeast region in the United States where gonorrhea and syphilis were most prevalent and where there remained an increase in other treatable sexually transmitted diseases (STD's) (Hader, Smith, Moore & Holmberg, 2001).

HIV has disproportionately affected African-American women from the onset of the epidemic. African-American women comprise the largest population as it relates to HIV to AIDS related deaths, yet the CDC has proclaimed that AIDS is no longer the number one disease. According to a 2003 report, 80% of adult infections were due to heterosexual intercourse ([www.cdc.gov](http://www.cdc.gov)). This high infection rate indicated to medical and social service providers that women still have little or no control as it relates to sexual intimacy in relationships. This sense of "helplessness" is complicated when a woman's male partner engages in sexual activities with another male and/or refuses to admit to substance abuse use.

The risk factor for HIV transmission by males who engaged in bisexual behaviors was extremely high (Land, 1994). Although this area of sexuality is still considered



taboo in the African-American community, Selik and associates, noted that African-American women were four times more likely than white women to have a male partner who was bisexual (as cited in Land, 1994). Men, who had sexual relationships with other men, did not identify themselves as gay or bisexual, but heterosexual as to the fear of stigmatization and homophobia within the African-American community (Boyd-Franklin, Steiner & Boland, 1995). This “camouflage” or lack of truthfulness has brought unparalleled suffering and loss to the African-American community. The tradition of pride and machismo within the male African-American community often restricts the discussion of sex, adultery and condom use (Wingood & DiClemente, 1995). Most HIV-positive African-American women are economically dependent on their male partner and feel powerless to change sexual practices that could reduce HIV and other sexually transmitted diseases (STDs) without repercussion which may result in physical, psychological or monetary damage (Coleman & Evans, 1998).

A CDC study in 1996 reported that intravenous drug use (IDU) accounted for forty-three percent of infected cases among African-American women (CDC, 1996). A 2003 report noted a decrease in this area of infection to 19% ([www.cdc.gov](http://www.cdc.gov)). This figure included women who engaged in sexual activities with others who injected drugs. Although there was a decline in the intravenous drug infection, the risk for contracting HIV/AIDS remains. The reasons are because of the cultural, community and economic barriers that make it difficult to obtain new needles or cleaning solutions such as bleach to clean one’s needles (Hutchinson, 1992).

Women who utilized drugs were not aware of their HIV health status until they

had a baby or were hospitalized due to an illness that is associated with HIV/AIDS. The illness or opportunistic infection (OI) are presented in the form of (in order according to the CDC) pneumocystis carinii pneumonia (also known as PCP-the leading cause of death among people with AIDS), candidiasis, bacterial pneumonia, wasting (loss of body weight, fat and muscle mass) and mycobacterium avium complex (better known as MAC-one of the most common AIDS defining illness) (Project Inform, 1998). African-American women are diagnosed later and are less likely to utilize medical services due to being uninsured, under-insured or because of her distrust of the medical profession. They are more likely to develop complications that may result in an early death.

Women also recognize the strong stigma that is associated with vertical transmission (Jackson, 1998). In 2000, African-American children accounted for 65% of all reported pediatric AIDS cases ([www.cdc.gov](http://www.cdc.gov)). HIV/AIDS continued to have a strong presence in the African-American family and community. A woman's responsibility is to protect her children. If the child is born HIV-positive, then it is the responsibility of the HIV-positive mother to provide for the child. A woman sometimes has to take on the responsibility of caring for the sick and dying spouse who infected her as well as provide for her HIV-positive child. Maintaining the demand of caretaker, wife, mother and head of household consumes most of her time and often the HIV-positive woman's health is neglected.

There are two additional categories of women who comprise the growing number of women infected by HIV/AIDS. The first category is older women. Within the past five years, there has been an emergence of older women (60 years and older) who have

been diagnosed with HIV or in some cases full-blown AIDS (Villarosa, 2003). Current studies are focused on this population. Physicians often do not question these women about their sex lives or past substance abuse history unless it is noted in their self-disclosure paperwork. The symptoms that women in this age group display are often misdiagnosis as a part of aging and a positive diagnosis can go undetected until it is too late (Siverson, 1999).

Current research on this group includes investigation of treatment options, which are available for a population that has other health issues that are deemed more important. HIV-positive women who comprise this population report that they received a positive diagnosis after the death of a spouse or partner. Self-reports can range from an extramarital affair, history of substance abuse, surgery (before the screening of blood), or unprotected sex (Siverson, 1999).

Lesbians comprise the second group. Women in this group are thought to have the lowest ratio of HIV sexual transmission. Further research revealed that lesbians represented in this category have a history of previous intimate relationship with a man or injection of drugs ([www.cdc.gov](http://www.cdc.gov)). According to a Kingsley report, self-identified lesbians knew that the male partner from the previous relationship identified as gay or bisexual . A published article reported women who identified as lesbian and were infected with the HIV virus reported risk factors of rape, paid sex work, sadomasochism with bloodletting, tattooing with shared needles and blood transfusions (prior to 1985) (Norman, Perry, Kelly & Roffman, 1996).

Several factors were the reason for under-representation of lesbians in HIV/AIDS

research and prevention programs. Factors included that lesbians were not asked the same health-risk screening questions as gay males, fears of disclosing same-sex sexual behavior, homophobia within the medical profession and the failure of service providers to understand the correlation of risky sexual and drug-using behavior (Norman, Perry, Kelly & Roffman, 1996). Depression, alcoholism, lack of access to health care and the lack of education and prevention programs that are specific to lesbians have contributed to lesbians being diagnosed later with the disease (Norman, et al, 1996).

The most frequent representation of women who have been identified as most at-risk for the epidemic are: women who are from inner city communities, lower socioeconomic levels, who are unemployed or underemployed, who have poor educational skills, who are single mothers with 1-3 children, and are disenfranchised (Quinn, 1993). These women are more likely to utilize the emergency room as their primary provider. Unfortunately when employing such service, a woman is more prone to be misdiagnosed and least incline to follow-up if she is given a HIV/AIDS diagnosis.

### Psychosocial Factors

The greatest challenge and fear for HIV-positive women is stigma associated with the disease, fear of abandonment by family and friends, rejection by others and lack of support services to assist with daily living (Hader, Smith, Moore, & Holmberg, 2001). In addition, a woman may find herself experiencing anxiety, depression, anguish, guilt and grief (Clark, Linder, Armistead & Austin, 2003). Being HIV-positive, African American, and a woman poses further discrimination. Sexism, racism, classism and homophobia are

psychosocial issues that infected women encounter (Rolands, 1996). A study by Kyle and Sachs, suggested that when a HIV positive status is given a person's life is reduced from that of independence to dependence (Kyle & Sachs, 1994). The dependence is carried to all area of a person's social support network.

The fear of rejection by the family unit is real and visible in some families. The constant explanation of how a woman acquired the virus along with the outdated but still used belief that HIV/AIDS is contagious, and fear of public ridicule are all psychosocial aspects that HIV women contend with if she makes the decision to disclose her health status. For most women, denial is a coping skill utilized to function with their HIV/AIDS diagnosis. Denial is used to ease the fear of isolation and rejection that she fears will happen if anyone discovers her health status (Boyd-Franklin et al., 1995, p. 100). A study conducted with HIV-positive women revealed that denial served two purposes (Demi et al., 1997, p. 377-379). The first purpose is denial of the existence of the illness and the second purpose is denial of the impact of the illness on the one's life. These denials often delay the seeking of treatment in fear that one will be recognized at the local HIV clinic. A woman with an established and supportive support system is able to continue living and not be judged, as harshly for her health status as a woman who's support system is weak and non-supportive. A newly diagnosed HIV-positive African-American woman may seek one or several forms of support from members of her support network.

## Social Support and HIV-Positive African-American Women

The *Encyclopedia of Human Behavior* (Lepore, 1994) defines social support as: “resources from the social environment that can be beneficial to psychological and physical health” (p. 247). Social support originates from an individual’s social network of friends who offer regular social contact. According to Magill, there are five major outcomes which constitute social support: “...1) the perception of a positive emotion toward oneself from another, 2) having another person agree with one’s beliefs or feelings, 3) encouragement by another person to express one’s beliefs or feelings in a non-threatening environment, 4) the receipt of needed goods or services and 5) confirmation that one does not have to face events alone, that others will be there when needed.” (Lepore, pp. 247-248).

An HIV-positive African-American woman’s social support (formal and informal) is used to buffer the impact of her diagnosis. The informal support systems are comprised of the family and nonkin associates (i.e., friends, neighbors and church members) (Billingsley, 1992; Neighbors & Jackson, 1996). Formal support systems usually consist of social service agencies and community resources. Formal support systems are created as the result of demands based on the needs of the community in which the woman resides.

An early definition of social support was “...accessible to an individual through social ties to other individuals, groups and the larger community.” (Braithwaite & Taylor, 1992). This definition was expanded through research that focused on the principles of social support. The new definition presented social support as a perceived or actual

instrumental and/or expressive provision supplied by the community, social networks and confiding partners. The expanded definition includes an individual's social involvement and the instrumental (the use of relationships as a means to achieve a goal) and expressive dimension (the use of the relationship as an end as well as a means) (Braithwaite & Taylor, 1986).

Other researchers noted that social support is the relative presence or absences of psychosocial support from significant others (Vaux, 1998). Authors refer to work done by Brenner which surmise that "...life satisfaction correlates to positively with total sources of social support." (Neighbors & Jackson, 1996, p. 127). In brief, Brenner's work focused on the direct correlation of one's social support network on one's quality of life. Brenner revealed that consistent support contributes to a person's quality of life. An individual is able to conduct their daily activities and knows that there is a system in place. For an HIV-positive woman, this leads to the reduction of barriers to healthcare, increase her ability to reach out to extended family members to receive needed kinship care and supplemental support.

Another aspect of social support incorporates more of a social structure approach. Duck (1993) explains that "the individual relationships are developed and managed by reference to socially and economically sustained models of what relationships are to be." (Duck, 1993, pp. 1-2). The social structure concept of social support focused more on an individual's choice of support depending on one's needs. Each established support structure has a specific use. Thus social support is conceptualized as types of

relationships with other with other individuals or groups that provide emotional, informational or tangible resources that are specific to one's mental, physical and spiritual needs.

### Types of Social Support

The various types of social support a HIV-positive woman receives from her support network are important in assisting her in her daily living. Emotional support is displayed in the form of physical affection and emotional intimacy. This type of support provides the psychological acknowledgment that there is love, understanding and comfort felt between individuals. Research has been conducted examining a correlation between HIV-positive individuals and their satisfaction with quality of emotional support from their support network. A study by Mitka, found that individuals who received quality emotional support as these individuals had established strong religious ties from their support network are less likely to have suicidal ideation (Mitka, 2002).

Informational support is the acquiring of relevant information or educational material about resources which are available and of which the person may not be aware. A study showed that HIV-positive individuals who received informational support about the progression of HIV from others who were HIV-positive were less likely to show an increase in depression (Hays, Turner & Coates, 1992). Informational support acts as a buffer that assists in the reduction of stress that causes HIV symptoms to manifest.

Lastly, tangible support is the most openly sought-after form of support, yet the most difficult to obtain and sustain over long intervals of time. This form of support is



displayed in the form of material or financial aid and is found throughout a woman's support network (Lepore, 1994). Financial assistance with bills, transportation to a medical visit or groceries are all forms of tangible support.

The task of identifying who in the HIV-positive woman's support network will be able to provide a particular form of social support begins with determining whether the woman has an established and functional support system. At the foundation of social support for most African Americans are the family, church and community (Marcenko & Samost, 1999, p. 45). The presence of these institutions is significant to the HIV-positive woman. The first support system that a person has is the family.

### Family Support

The family is the most important and influential formal support system that is the foundation to society. African-American families, as noted by in writing by Dr. Wade Nobles, "...stretches and diminishes in response to external conditions that impact on it" or what is noted as family elasticity. (Nobles, Lawford, Cavill & George, 1987, p. 37). The immediate family may consist of members from the extended family network (kin or nonkin). The extended family kinship within the African-American community is a major source of social and emotional support (Pillari & Newsome, 1998, p. 193).

The family is the foundation from which other social support networks will be established and maintained. Support is offered when problems or serious health issues arise in a family (Bowles & Kingston, 1998, pp. 337-338). HIV and AIDS has infected and affected family members, especially African American and Hispanics, which has

resulted in the individual returning to the family base. The family is a refuge in which an ailing woman can seek assistance. An HIV-positive woman seeks the family as it represents a system where she is known and can obtain support with or without disclosing her HIV status. A woman's returning or dependency on her birth family may occur out of necessity to assist with her children's needs. HIV-positive women tend to have at least two children and the support that will be needed to assist with the legal aspects of caring for not only the infected woman but also her affected children will affect the family network as a whole (Loon, 2000, p. 152).

Emotional and tangible supports are the highest requests from the family support network. Requests can range from assistance with bills, childcare, and transportation to accompaniment to a medical appointment. A family's response to a woman's positive status depends largely on the mode of transmission and her role(s) in the family (Dicks, 1994, p. 124). Other factors mentioned included the interaction between the family and the woman and the family's reaction to stress, the family's spiritual beliefs and its value base (Dicks, 1994, pp. 124-130). As the disease progresses and a woman is no longer able to care for herself, her roles and responsibilities may fall on her children (if he/she is of age) and her family (immediate and extended).

The recognition and engagement of extended family can be crucial to the wellness of a HIV-positive woman and her children. Throughout African-American history, the extended family has played an intricate part of assisting the family in times of crisis, illness, celebration or death (Pillari et al., 1998, p. 192). In the era of HIV/AIDS, the extended family is greatly valued. The extended family was associated with the helping

tradition among African Americans. The extended family successfully established the care-giving institutions in the African-American family and community. Extended family members were known to provide emotional support during periods of crisis (McAdoo, 1998). Martin and Martin further suggested that mutual aid, social class, cooperation, male-female equality and prosocialization of children were identifiable traits associated with the Black extended family (Martin & Martin, 1978, pp. 67-69). Billingsley shared a similar view as Martin and Martin. Billingsley concept was that the African-American family has the capability of adaptability (Billingsley, 1992, pp. 69-73). The adaptability of the family structure and pattern were contingent on the pressures and opportunities that the family encountered.

Robert Hill continued along the same line and identified five strengths of the African-American family. The strengths were adaptability of family roles, strong kinship bonds, strong work orientation, strong religious orientation and strong achievement orientation. The strengths of the adaptable family roles and kinship bond are present when an HIV-positive woman relinquishes her role as caretaker and become the person who is receiving care. It is not uncommon for a woman (if single or widowed) and her children to return home to her parents/guardian. In this situation the grandparents repositions themselves into parenting by rearing their grandchildren as the mother's health declines (Loon, 2000). The return of the infected woman can cause stress on the grandparents and other extended family members. The stress is especially noted in families that have experienced losses, which may include the loss of loved ones to substance abuse, homicide and/or suicide. The losses may result to a decrease in support.

The increased number of HIV-positive women in the African-American community has led to HIV becoming a “multigenerational family disease.” Research by Boyd-Franklin, (1995), indicated that an affected woman has the role of caretaker in her family as well as that of spouse, mother and provider (Boyd-Franklin, 1995). Her primary concern is caring for her children with little interruption and attending to the legal issues of who will tend to them when she becomes too ill as well as after her death. If networks and peer groups disintegrate or as the family structure shifts, a woman can experience feeling of isolation. This can cause her to seek other areas of social support. Some African-American women elect to revert to or seek spirituality guidance.

### Spiritual Support

Spirituality or more specifically, the church is the second most common institution where the HIV-positive woman may seek social support (Dunbar, Mueller, Medina & Wolf, 1998). The church is one of the first agencies of formal support that provides informal social support. The role of the African-American church has and will continue to be that of a place of social and spiritual support. Research that was conducted by Veroff, Douvan and Kulka, found that African-American women were more likely to use prayer as a coping strategy in response to physical health, interpersonal, emotional and death issues (Neighbors & Jackson, 1996, pp. 131-136).

Another study discussed the psychological and spiritual growth in women living with HIV (Dunbar, Mueller, Medina & Wolf, 1998, p. 146). Participants in this study recalled their experiencing an unexpected positive outcome when faced with the

diagnosis of HIV. The positive outcome was based on establishing or rebuilding a spiritual foundation with God or a Higher Power. The renewed relationship the women expressed contributed to a feeling of calmness and a sense of determination to continue living with the HIV status. Prayer and meditation were mentioned as tools used to assist with the transformation of living with HIV/AIDS instead of allowing the disease to be in command of every aspect their lives.

Bargaining is one of the five stages of behavioral responses that Kubler and Ross applied to people dying from HIV/AIDS (Dunbar et al., 1998, p. 149). The bargaining agreement was established between an HIV-positive woman and her spiritual being. The agreement focused on prolonging of one's life. If her lifespan was lengthened, promises of a significant change in her lifestyle would occur. Changes would vary from relinquishing of substance use, to changing of sexual behavior to becoming medically compliant.

The African-American family unit is an intricate part of the church. The African-American church has assisted in the preservation of the African-American community and social reforms (Nobles, 1988, p. 47). African Americans frequently become involve with a church at an early age and tend to develop and/or maintain a connection with the church as they come into adulthood. The HIV-positive woman's involvement in the church (e.g., frequency of attendance, membership and involvement in church committees) determines the level of support from church members (Barroso, 1997, p. 556). The church and members of the congregation are often providers of informal social support (Sanders, 1997, pp. 373-376). An additional study confirms that an HIV-positive

woman will seek the emotional support availability from church members and non-relatives before seeking the help from professional mental health services (Sanders, p. 373).

When seeking spiritual guidance the HIV-positive woman should prepare herself for negative reaction from the church or spiritual institution (Demi et al., 1997 pp. 377-380). An HIV-positive woman who has maintained a role within the church can assess the position that her pastor has as it pertains to HIV/AIDS and how the pastor responds to members of the congregation and the community at-large who are infected with the disease (Gant, Stewart, & Lynch, 1998). The influence of the message that comes from the pulpit is critical to how information is assimilated by the congregation who in turn conveys a message of support or non-support to those who are infected. The church serves as the institution that assists a woman in establishing or re-establishing her identity (Pillari & Newsome, 1998, p. 192). The HIV-positive woman may seek validation and develop a sense of belonging within the church community (Pillari & Newsome, 1998, pp. 192-194). A woman's attempt to achieve these goals may contribute in raising her self-esteem and empower her to live.

Over the past 8 years, the African-American church publicly acknowledged that HIV/AIDS impacts the African-American family unit ([www.thebody.com](http://www.thebody.com)). In acknowledging the pandemic of HIV/AIDS within the African-American community, some churches have established AIDS outreach ministries that provide limited social services to people within the community. A HIV-positive woman reluctance to disclose her HIV status to the church because of the fear of being stigmatized may also need

assurance that her pastor is willing to provide pastoral counseling without passing judgment. The thought of disclosure affects a woman's emotional state. A woman may fear her family can face ostracism or discrimination against because of her health status (Rowe & Ryan, 1998, pp.114-115). Secrecy is equated with safety (Boyd-Franklin et al., 1995, p.57). Emotional support and in severe cases, monetary support are immensely valued and some churches are in the position to provide these types of support. If a woman's HIV status is revealed within the church congregation support maybe reduced or terminated. The need for additional support may then be sought from the community and the agencies that provide services within that community.

### Community Support

Edell describes community as "...a group having common interest or a common identity." (Edell, 1998, p. 49). Further expansion of this definition examined the dynamics of the people who comprise a group or community. The people in the community, "...depend on one another, make decisions together, identify themselves of something larger than the sum of individual relationships and commit themselves for the long-term to their own." (Shaffer & Anundsen, 1993, pp. 24-32). This definition can be applied to communities of color. Majority of people of color tend to gravitate to communities that are representative of individuals who look like them and share similar cultural values. These values are seen in the four aspects of the African-American communities (Billingsley, 1992). The first aspect is that African Americans tend to live in neighborhoods where there are other African Americans. This may occur due to

economic or racial reasons but for the most part, people are drawn to areas where there are people who are similar to them.

The second aspect of community is the shared values that most African Americans still embrace. The values of education, work ethics, family and sense of community all encompass the African-American shared value system. The third aspect of community is African Americans identify with their heritage and causes that impact the African-American community. Informational discussions about issues that may impact African Americans in general are relevant to the community as a whole. The final aspect of the African-American community is the institutions, agencies, organizations and services that were designed to primarily serve African-American people and their families. African-American communities are composed of the family, extended families, religious sectors, learning and lending institutions and community agencies (Pillari & Newsome, 1998, pp. 192-194).

An African-American woman often seeks a connection within the community in which she resides. The interaction between a woman and her community creates an established culturally shared value system. The shared value system of the African-American community (which includes all of the systems and subsystems that a woman is involved) is an intricate part of the HIV-positive woman's life. It is within her community that she will first seek to locate resources that are available to her. If the resources are unavailable to her within her community, she will have to communicate with other systems or subsystems that extend beyond her community. Communication with other subsystems can include the county's Child Protected Services (CPS) as the



new transformed woman makes attempts to re-establish a relationship with her children who are in the system or with the immunologist who monitors the HIV-positive woman's health.

Communication and the need for constant feedback fuel the heart of most communities. Communication allows a person to receive the information from the community as a whole while allowing the person seeking the information to retain their individuality. Communication within the community can be obtained from systems and subsystems that provide formal and informal support. Forms of communication may include written materials (brochures, applications, etc.), visual advertisements (flyers or billboards) or verbal instructions of where to go for assistance.

The community is often the base where information is assimilated and dissimulated. The escalating HIV crisis in the African-American community has caused some community leaders to demand more HIV/AIDS resources, prevention programs and drug treatment facilities. Community leaders have requested that the clergy take a more proactive role and to mount a war against HIV/AIDS. Some communities have formed alliances with local HIV/AIDS service organizations to provide free or low cost education/information about HIV/AIDS. Depending on the community in which the HIV-positive woman resides, some of these options may not be in place or there may not be a leader who would be willing to prompt such an action in fear of being ridicule.

The impact of urban decay along with the manifestation of drug and alcohol abuse, soaring crime rate and poverty may contribute to the loss of community social

support for an HIV-positive woman. Agencies that cater to HIV-positive women who are addicted to drugs or alcohol may not be available in a woman's community or accessible by public transportation. A woman should possess the desire and the financial support necessary to venture outside of her community to receive services. Agencies should be able to not only address the addiction that the woman is battling, but provide additional social support and resources in the areas of affordable housing, transportation, health care, job readiness/employment training and education.

For an HIV-positive woman, her ability to navigate the social service system is imperative as it allows her to receive the necessary resources for herself and her children/family. Informational support as well emotional support can be achieved within the community as well as beyond the community if the woman possesses the determination and will to persuade the source. Even women with the most stable support system encounter roadblocks or barriers to support.

### Barriers to Social Support

Women in general are viewed as disenfranchised and disempowered because of gender, race and poverty (Land, 1994, pp. 355-360). African-American women have been ignored by society and are confronted with sexism, racism and classicism from within the African- American community as well as society on a daily basis (Williams, 1995, pp. 41-45). Attach to this social, psychological and family issues and the image appears overwhelming (Quinn, 1993,p. 305). The diagnosis of HIV-positive is an additional "ism" that they must endure and in most circumstances it is not the most

important issue. These isms” all become barriers that greatly influence a HIV-positive African-American woman to seek social support.

A major barrier in the African-American community is the belief that the medical profession, that is a part of the formal support system, utilizes its powers to assimilate and eradicate the African-American race. This barrier stems from the historical Tuskegee Syphilis Study that occurred from 1932 to 1972 (Quinn, 1993, pp. 307-310). In the study, 412 African-American men were injected with syphilis and never received information or education about the disease. The subjects also never received the penicillin therapy that the medical profession and government realized was effective in combating syphilis.

Documentation and the verbal storytelling of the Tuskegee Syphilis Study have and continue to be expressed throughout the African-American community. The belief was that the study was a form of genocide for African Americans. As HIV and AIDS continue to affect a large population of African Americans, the African-American media has questioned HIV and AIDS as being the latest governmental form of genocide (Quinn, 1993, pp. 310-312).

Taking the initial steps to begin HIV treatment is a major accomplishment in a woman's life. When medication is prescribed, barriers may occur with some women. African-American women who decide to take HIV medication may become non-compliant if they are required to take several pills at one time or if they experience severe side effects. A woman may feel that taking the medication or its side effects may arouse

suspicion from her family or friends. Her perception that she may not receive positive social support from her established support network may hinder her disclosure.

Midlife and older African-American women (45 years of age and older) are less likely to disclose their status and less likely to seek social support (Marcenko, & Samost, 1999, pp. 44-46). Women in this age group are often experiencing body image, change in family structure and in some cases, marital status. If the woman is involved in a sexual relation, disclosure of her status may result in the discontinuation of the relation. This may lead to the fear of isolation, stigma and shame. Women in this age group are also usually the caretaker for multiple family members, some even taking on the role of guardian for the grandchild who has already lost a parent to AIDS (Marcenko, & Samost, 1999, p. 46). The lack of outreach to this age group itself is a barrier for a women seeking social support.

Blaming the victim is a reason women may decide not to seek social support. Farmer mentioned in *Women, Poverty and AIDS* that blaming is recurrent throughout history as it pertains to epidemic diseases (Farmer, 1992, p. 27). Throughout the history of epidemics, especially sexually transmitted diseases, women have been singled out as carriers of diseases that infect men and children. The early history of HIV/AIDS reflected the same idea, depicting a positive woman as the carrier of the virus that infect unsuspecting male partner(s) and her unborn child. If poor, women have been depicted as drug addicts and prostitutes who infected the unassuming male population (Boyd-Franklin, et al., 1995, p 100). To take blaming the victim further, a HIV-positive woman may have a realistic fear to disclose her status due to the fear of domestic violence that

may occur if her male partner believes his masculinity or faithfulness is in question (Boyd-Franklin, et al., 1995, p.100). The abuse may lead to the woman's tangible and emotional support systems being interrupted or ceased.

The misconception or lack of education about HIV or AIDS and the pandemic it has caused in the African-American community is a barrier that is often overlooked. Reports and statistics from the CDC continue to inform the public that AIDS cases within the general public are decreasing. The statistics continue to reflect the white population not African Americans, especially African-American women. Statistics from an AIDS resource report found that AIDS among African-American women, age 35-44, was one of the top three causes of death ([www.thebody.com](http://www.thebody.com)).

A woman's participation in a community support group may be hindered by the meeting time of the group as well as the composition of the group (Barroso, 1997, p. 556). Difference in socioeconomic background may be a barrier for an African-American woman who is interested in attending a community support group. This factor may cause the woman not to actively participate in the group's dialogue due to the fear of not being articulate or the fear that the group would not be able to relate to her particular situation. These and other barriers can hinder a woman's search for social support that can be detrimental to the woman's health and her family. The HIV-positive African-American woman should be willing to weigh her options. She should exercise her decision to seek the various types of support from her network so that she can live with the disease or to ignore the support that is available to her and allow the disease to control her life.

### Quality of Life

When AIDS first appeared 20 years ago, it was considered a death sentence. The medical profession offered palliative care because there was no option. Palliate care is ...“care which is centered around the patient and family...will optimize the patient’s quality of life and reduce suffering while making the patient as comfortable as possible.”(www.hab.hersa.gov). In the late 1980s and early 1990s medications, known as prohiitors, became available and HIV and AIDS infected individuals’ lives expectancy increased and their participation in their daily activities improved (AIDS Community Research Initiative of America, 2000). The medical profession began to investigate the quality of life for these individuals and realize that HIV could be considered a chronic disease instead of the death sentence it had been for so long.

There is no set definition for the quality of life. However, there are similar concepts. Carr, Gibson, and Robinson defined the quality of life as “a holistic emphasis on the social, emotional and physical well being of patients after treatment to those that describe the impact of a person’s health on his or her ability to lead a fulfilling life” (Carr, Gibson, and Robinson, 2001, p.1240). The World Health Organization’s (WHO) conception of quality of life is similar as it states that “...the individuals’ perception of their position in life, in the context of the cultural and value systems in which they live and in relation to their goals, expectations, standards and concerns...” ([www.uib.no.doc](http://www.uib.no/doc)).

In a study that examines the quality of life and living with HIV quality of life was defined as “the many realm of a person’s well-being...health, pain physical and mental functioning.” (Vosvick, Koopman, Gore-Felton, Thoresen, Krumboltz &

Spiegel, 2003). The search for a clear and concise definition of the quality of life really is complex and is based on an individual's perception to continue his/her daily activities as well as to obtain personal goals.

### Quality of Life Scales

As a result of the need to understand the quality of life for individuals infected with HIV, health providers began to administer questionnaires. The questions for these scales focused not only on a person's health but how a person was able to manage their lives while dealing with side effects from medications, ingesting of numerous pills, fatigue and pain/neuropathy.

One of the most widely used questionnaires is the Karnofsky Performance Status Scale. A health care provider administers the scale every 3-4 months. Once completed the scores are assigned a global ranking to functional activities that are completed on any given day (Aranda-Naranjo & Davis, 2000). Another instrument that is administered to HIV-positive individuals is the Medical Outcomes Study (MOS-HIV). The questions on this scale were taken from a widely validated health status questionnaire and assess health-related quality of life information for HIV. The areas that are explored include the aforementioned as well as mental health, health perception and health transition (Stein, 2001). Other quality of life questionnaires contain sub-scales that particularly address specific quality of life concerns related to HIV or AIDS diagnosis. These sub-scales may include rating of HIV stigma, disclosure, intimacy and drug adherence (Rapkin, 2000).

Quality of life questionnaires ask participants to rate their perception of their

current health. The responses to the questionnaire depend not only on a woman's perception of her health but also her ability to care for herself, her children, partner/spouse and or other family members and to complete her daily living activities.



## CHAPTER III

### THEORETICAL FRAMEWORK

The theoretical significance of this study was to expand on the existing paradigm of how social support is related to the quality of life of an African-American woman with HIV. The independent variable is social support and the dependent variable is the quality of life. The research question and hypotheses of the study are stated as follows:

Research Question: Is there a relationship between an established social support network and the quality of life for an African-American woman who is HIV-positive.

Hypothesis: There is a relationship between an established social support network and the quality of life for an HIV-positive African-American woman.

The theoretical framework for the predicted relationship is grounded in the General System Theory. The General System Theory is used to show that there are relationships and interactions that occur between an individual and the subsystems that encompasses an individual's support network. The theory also emphasizes constant assessments and adjustments are always occurring as it pertains to what's occurring in an individual's life (Zastrow & Kirst-Ashman, 2004, p. 24). As a woman's support systems evolve and become connected, systems and their information may sometimes overlap. The information that is processed by the woman will assist in the evolvement of her

support system and her ability to manage life in general.

The importance of the family (immediate and extended), spirituality and support systems are incorporated in this theory. Biologist Ludwig von Bertalanffy formulated the General System Theory in 1928 (Bertalanffy, 1968, p. 11). Bertalanffy proposed that: “...a system is characterized by interaction with the environment, exhibit strategies of self maintenance, and experience cycles of birth, growth, maturity and decline...” ([www.bertalanffy.org](http://www.bertalanffy.org)).

The theory recognizes that all living systems, which are considered open system, depend on their environment to exchange matter, energy and information (Zastrow & Kirst-Ashman, 2004, pp. 11-12). As interactions occur within the environment, the person acquires new properties or information

An individual is the main part of their personal system. An individual’s system consists of the “ bio-social, psychological and spiritual system” (Zastrow & Kirst-Ashman, 2004, pp. 12-13). A system is designed to interact with other elements of a person’s life in an orderly fashion and each system has established boundaries that characterize that system and its particular function. An HIV-positive woman’s environmental system includes the family, social and work communities, or mezzo system. The family system is divided into immediate and extended members that comprise the micro systems (Zastrow et al., 2004, p. 12). Subsystems within the community include education, religion, social services, employment and health care institutions.

The environment in which a woman lives is essential for her development. The two interact and mutually influence each other, which operates to maintain a homeostasis environment in all areas of a woman's life. According to Hepworth and associates, if a woman's environment is abundant with a supportive social network, this will serve as a coping mechanism for her disease (Hepworth, Rooney, & Larsen, 1997, p.268). However, the opposite can be stated if the woman has a scarcity of supportive resources. The shortage can lead to the woman resorting to a form of deviant behavior (e.g., drug and alcohol usage, sex for money).

Communication and transactions of information are necessary to achieve equilibrium within a woman's system. For a HIV-positive African-American woman the transaction of information from her various systems and subsystems, are necessary for her survival. The contact and communication between systems or interface, usually results in the each system knowing what is its responsibility and expectation. The movement of information from a person's environment into the system is known as input (Zastrow & Kirst-Ashman, 2004, p.5). Input can be viewed as positive information that the woman may accept or negative information that she may reject. The movement of information from the system to the environment, known as output, occurs when the woman either rejects the information or seeks additional information from her support system (Zastrow & Kirst-Ashman, 2004, p.5). The willingness to be open to new information (positive or negative) will assist with a woman with building a more extensive social support network.

Negative equilibrating feedback acts to restore stability to the system. Positive equilibrating feedback raises the awareness of an issue to a higher level. The goal of both positive and negative feedback is again to achieve a level of equilibrium within the system. The system process of constant input and output of informational support from other support systems will provide the necessary information that would be needed for a positive dialogue to occur. Positive feedback occurs when a particular issue or crisis is stabilized. The awareness of that particular issue has been achieved and it is no longer at the initial level in which it was obtained. Because a person's support systems are interconnected, positive feedback should occur throughout the individual's environment that will result in the HIV-positive woman living longer and maintaining a better quality of life.

The System Theory also focuses on the values and belief system that a person establishes and utilizes. Bertalanffy termed this as perspectivism (p.247). The earliest establishment of the values and belief system is found in the family system in which a person is born and raised. Influences from systems within the community (educational and spiritual institutions) also shape a person's perspective. The perspective that a woman has about HIV will greatly influence her success in reaching out to her support system for help (emotional, financial or informational).

#### Definition of Terms

For the purpose of this study, the following terms are defined.

**HIV-positive:** The human immunodeficiency virus antibodies are present in the blood of

an individual.

**African-American Woman:** An American female of predominantly, or at least partial African descent.

**Social Support:** The exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well being of the recipient.

**Quality of Life:** An individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards and concerns.

**Social Network:** The map of relationships between individuals, indicating ways in which they are connected through various social familiarities.

## CHAPTER IV

### METHODOLOGY

This chapter provides a description of the methodology used to conduct the study. It includes the research design, site, sampling procedure and selection, and analysis.

#### Research Design

An explanatory descriptive research design was used to examine the relationship of social support and the quality of life among African-American women who are HIV-positive. This study was conducted on HIV-positive African-American women who resided in Alameda County. The participants ranged in the age group of 18-44. The participants were administered two questionnaires and asked to answer the questions. The first of the questionnaires, the Social Support Questionnaire, was divided into two sections. The first section focused on demographic information and the second section focused on the health and quality of life of the participant.

The second questionnaire was the Social Support Appraisal Scale. This scale asked the HIV-positive African-American woman to rate whom she perceived provided the most support within her social network.

#### Site

There were four agencies that were chosen to recruit participants. All of the agencies were located in Oakland, California. Three of the agencies were located in

downtown Oakland and were accessible by mass transit. The fourth recruiting site was located in an urban community hospital on the eastern part of the city. This site was also accessible by mass transit.

Three of the agencies, located in downtown Oakland, provide long and short-term case management services to individuals who are infected and affected by HIV and AIDS. Additional services that are provided by the agencies include support groups, psychosocial and mental health assessments and vouchers for food and transportation. The demographics of the agencies clientele are mostly African Americans with a small percentage of Latinos and Africans. As it pertains to which gender utilizes the services that are available to HIV/AIDS patients, males are largely representatives of individuals who are enrolled for services with women and transgender being represented respectively.

Of the three downtown social service agencies, only one provides services exclusively to women and their families. Services include support groups, updates on the latest clinical trials for women, retreats, medical and educational seminars. Although quite small, the agency has been around for over 10 years and has been recognized nationally and internationally. African American, Latino and Native American women compose the small group of women who utilize the agency's services.

The fourth location is the county hospital HIV ward that refers participants to the aforementioned agencies. The hospital is a much needed venue where the county's residents who are underinsured, uninsured or have no health coverage can receive medical care. The HIV ward provides primary and urgent care and brief care

management intervention. The staff also assesses the other medical and psychological needs of an HIV-positive woman and provides referrals to other medical departments within the hospital. The ward's racial make-up of patients is mostly African Americans, Latinos, Africans and Caucasians. Males again, represent individuals who are actively receiving and maintaining medical care. The surveys were conducted at the two larger HIV service agencies that were located downtown and had referred the most participants. Both of the sites were handicapped accessible. Each of the agencies provided a room that was located in an area of the agency where there were little or no disruptions. The setting of the room was very informal.

#### Sampling Procedure and Selection

Due to the nature of the study (explanatory and descriptive) and the emphasis on a particular group (HIV-positive African-American women), convenience sampling was used to obtain the participants. The author administered the questionnaire. Thirty-six women contacted the recruiter and expressed an interest in the study; however, only twenty-eight HIV-positive African-American women elected to participate in the study.

An initial meeting was held between the author and the executive directors and program manager at each recruiting site to discuss the purpose of the study, review the questionnaire and plan the recruitment process. Subsequently, second meetings were held with two executive directors, two program managers and members of the staff at four different agencies. The recruiters from the four agencies were informed of the requirement for the study. The criteria for the participants selection were (a) African



American; (b) born female; (c) 18-44 years in age; (d) HIV or AIDS diagnosis; and (e) not a caregiver or family member who did not have a HIV-positive or AIDS diagnosis. The purpose for this exclusion was to ensure the study focused on African-American women who live with HIV or AIDS and their social support network did not include individuals who were affected by the disease.

Each staff member received and reviewed a copy of an informed consent form (see Appendix A), the demographic questionnaire (see Appendix B) and the Social Support Appraisal scale (see Appendix C). All staff was encouraged to emphasize to the potential participants that there would be no breach of confidentiality since no names or other identifying data would be used. The staff members were also urged to inform the clients that due to lack of funding, no incentives could be offered.

A poster that announced the study was placed at the recruiting sites and the agency's staff members were instructed to inform potential participants about the study. The author's contact number was placed on each flyer allowing any participant to call if she had questions about the study. Also included on the poster was the assurance that the study was strictly voluntary, no incentives would be given and all information was confidential.

Interested candidates were asked to contact the number listed on the poster and schedule a time she could participate in the study. Once contacted, each participant was assigned a time slot and date for the interview. Participants were also given a choice of sites for the interview. Within 24 hours from the initial contact with the participant the

questionnaire were administered. Each participant was informed that if she was unable to meet with the interviewer at the scheduled time, the interview could be rescheduled.

Upon completion of the survey, the interviewer answered questions raised by the participant and thanked each for participating in the study. Before leaving, the participants were again reassured that the questionnaires were confidential and that all records would be destroyed after the completion of the study.

#### Human Subjects/Consent

All considerations were given to confidentiality and to ethical and moral issues. All participants were informed of their rights as participants during the solicitation for the participation process as well as at the beginning of the interview. Each participant received an informed consent form at the beginning of the study (Appendix A). The interviewer read the content of the form aloud and allowed the participant time to ask questions. To proceed with the study, the participant was asked to write the date in which the survey was administered and her choice of code that would be known by the interviewer, in the signature area. Each participant received a copy of the informed consent for her records.

#### Data Collection Process

The actual process to secure the cooperation of the four agencies took two months of planning. Appointments to meet with the various executive directors and staff took an additional 45 days. The author spoke with each executive director to determine what documentation of agreement needed to be constructed in order to present the study to the clients. Two of the four sites requested a letter of participation

(see Appendix B). Upon the presentation of the letter, the author was allowed to proceed with the study.

Upon the agreement by the agency's directors, the staff informed all potential, qualified participants about the upcoming study. The staffs were instructed to tell the participants only the basics about the study, which included that the study focused on women's health and their social support network. Additionally, participants were told that the study was a paper questionnaire and would only take a few minutes to complete. The staff was asked to reiterate that no incentives would be offered from the interviewer for participating in the study.

The interviewer understood that due to the nature of the stigma associated with HIV/AIDS in the African-American community the sample population would be small. The interviewer was also aware that the lack of incentives reduced the number of potential participants for the study. Participants who volunteered for the study but did not follow-up with their scheduled time were contacted and rescheduled. If a participant did not show for the second scheduled time, she was omitted from the study and her case manager was informed. Participants who completed the questionnaire were allowed to ask questions upon turning in the questionnaire and each was given the interviewer's contact number to call if they had questions up to 30 days after completion of the questionnaire. The data for the study were collected over a two month time period.

### Instrumentation

Two separate questionnaires were administered for the data collection process. They included the Social Support Questionnaire and the Social Support Appraisal Scale.

*Social Support Questionnaire.* The anonymous social support questionnaire (Appendix C) was divided into two sections. The first part of the questionnaire was composed of six demographic questions that were taken from a survey that was utilized in a larger study gathering demographic information of HIV-positive women in the South (Southern Women Health Project, 1999). The six questions used for this particular study focused on information about the participant's age group, education, marital status, living arrangement, employment status and the year of a positive diagnosis. Participants were asked to circle the categories which best represented their answers. They were informed that there were no wrong answers.

The second part of the questionnaire consisted of six open-ended questions on health and quality of life. The questions used were from a larger quality of life survey that is part of the NIAID AIDS clinical trials that is administered to AIDS patients in medical facilities (National Institute of Allergy and Infectious Disease, 1987). The questions allowed the participant to rate her current health and her health six months ago. The areas that she was asked to rate included her ability to walk, bathe or dress, socialize with relatives and friends, attend medical appointments, and her exercise regiment. Responses to all questions were a 5-point rating scale that measured respondent's quality of life ("Excellent" to "Poor") as she lives with an HIV/AIDS diagnosis.

*Social Support Appraisal Scale.* The 23-item scale (Appendix C) asked the participant about her relationships with her family and friends. The scale asked the participant to rate the truthfulness of each statement. Responses to the statements were a 4-point scale that ranged from 1-Strongly agrees to 4-Strongly disagree.

The participants were allowed as much time as needed to complete the questionnaires. The quickest time of completion was 12 minutes and the longest time was 40 minutes. The average time of completion was 25 minutes. Three individuals required assistance reading the questions. The questions were read aloud by the interviewer and the women were instructed to record their answers on their assigned questionnaire.

#### Data Analysis

All data collected were analyzed using the Statistical Package for the Social Sciences (SPSS) for Windows program. Bivariate analyses were used to compare the responses for the various demographic groups within the study on various items. Through the preliminary analyses the study relied upon the Pearson chi-square for statistical significance of relationships. Bivariate techniques included the ANOVA test for difference in means on the Social Support Appraisal scale and its sub-scales (Family and Friends subscales), and the Pearson chi-square statistic to test for independence of categorical variables. Where appropriate, categories were collapsed in order to increase cell sizes.

## CHAPTER V

### PRESENTATION OF FINDINGS

The purpose of this thesis was to investigate the relationship between social support and the quality of life among HIV-positive African-American women. This study was conducted by surveying 28 HIV-positive African-American women recruited from four HIV agencies in Oakland California. The participants were asked to record their responses to questions representing quality of life and social support. Their answers were coded for analysis purposes. The findings are presented as follows: (a) Survey Scoring, (b) Analysis of Demographic Information, (c) Analysis of Health and Quality of Life Scale, and (d) Summary.

#### Survey Scoring

For each respondent (n=28) there were three sections that generated a total of 37 possible responses. Responses for section one of the social support questionnaire focused on demographic information. There were a total of six questions in this section with possible scores that ranged from 5 to 25. The last question for this section allowed the respondent to record the actual year she received her HIV or AIDS diagnoses.

The next section of the social support questionnaire assessed the areas of health and quality of life. Participants were asked to rate perception of their current health as well as their health 3 months ago. In this section there were a total of eight questions and

possible scores ranged from 8 to a possible 40.

The last part of the survey was the Social Support Appraisal Scale (SSA) that had a total of 23 questions. Scoring ranged from strongly agree (1) to strongly disagree (4) with total possible scores of 23 to 92. Within the scale were two subscales that rated social support among a woman's family and friends.

A combination of the total scores from the surveys indicated that the lower a score a woman has, the more support she perceives that she has. The same rules apply to the two subscales of family and friends.

#### Analysis of Demographic Information

In order to assess how respondents replied to the survey, the results of each question have been presented individually. The findings regarding demographics consist of participants response according to age, marital status, living situation, areas of employment and length of time living with HIV or AIDS. The first question asked the participants to circle the age group that was closest to their age (see Figure 1).

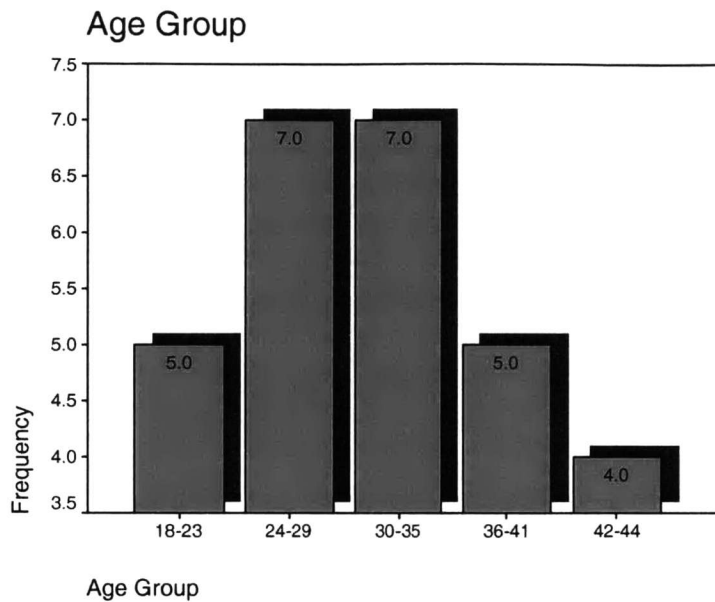


Figure 1. Age Group-Frequencies (Bar Chart)

Nothing tested statistically significant according to age. The age groups of 24-29 and 30-35 years were the two groups that had the largest number of participants (7 each). Overall, the total Social Support Analysis (SSA) scores show that the respondents in the age groups of 30-35, 36-41 and 42-44 years had a strong support system. The mean score for total support was 42.79 or 43. This suggested that, overall, women felt supportive of themselves and felt supported by family and friends. Respondents in the age group of 30-35 and 36-41 years felt that they received strong support from their family. The average score for the cohort survey was 14, suggesting that overall women felt somewhat supported by their family. All of the respondents, regardless of age, felt that they had a strong friend support network. The average friend score for the cohort was 10, suggesting that overall women felt they had a strong support system amongst their friends.



The next question requested the participants to identify their marital status (Figure

2)

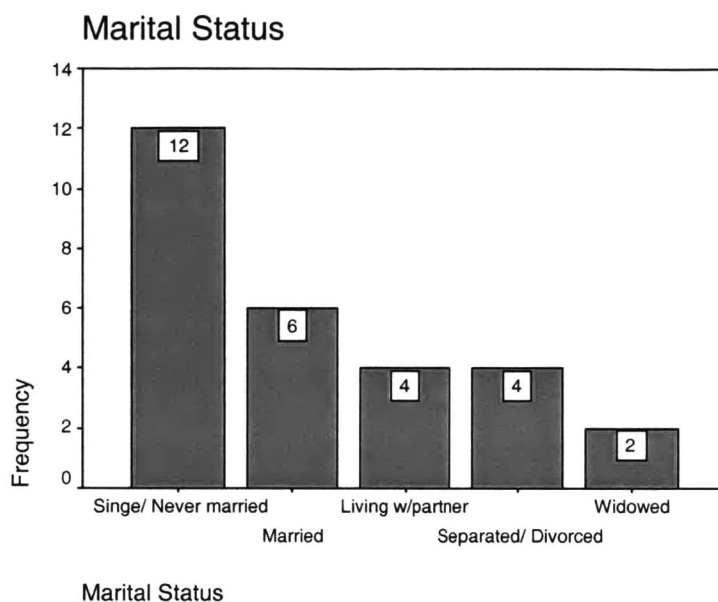


Figure 2. Marital Status-Frequencies (Bar Chart)

Nothing tested statistically significant as it pertains to a HIV-positive woman's marital status. Most of the respondents (12) identified as single/never married followed by the next highest represented (6) group being married. These two groups along with women who identified as living with a partner felt that overall they were supported by family and friends.

In reviewing the subscale of family support in this same category, women who identified as married felt supportive by their family. The two participants, who were widowed, felt that their family was not supportive. The subscale of friends support noted that all of the participants regardless of their marital status noted that their friends

provided strong support. Women who identified as living with partner scored the lowest, with the lowest score possible score being 6, with an average of 8.50.

The next question assessed the participants living situation (Figure 3).

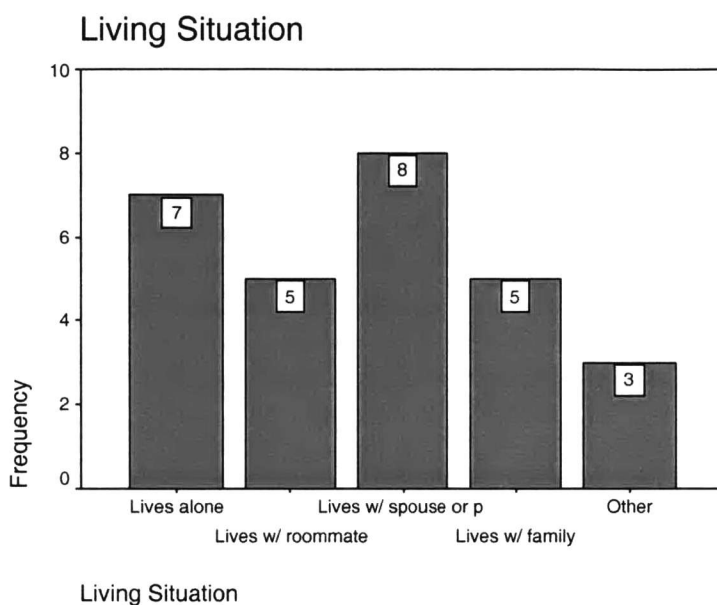


Figure 3. Living Situation-Frequencies (Bar Chart)

Eight of the women reported that they lived with their spouse or partner, followed by seven of the women responding that that they live alone. Overall, all of the participants felt supportive regardless of their living situation. Women, who responded that they lived with a roommate, felt they had strong family support. All of the participants felt their friends were very supportive, regardless of their living situation.

The next question assessed the participant's education level (Figure 4).

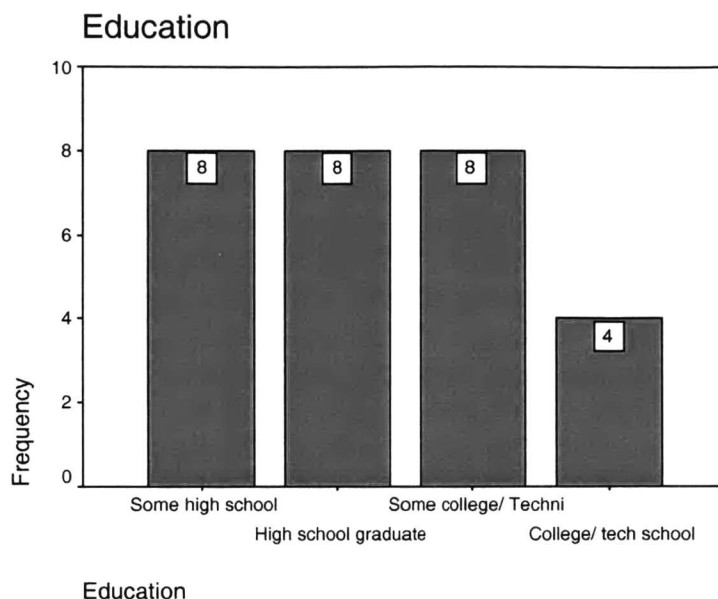


Figure 4. Education-Frequencies (Bar Chart)

Although nothing tested statically significant the overall and family scores were almost significant. Twenty of the women completed high school and 12 continued on to higher levels of education. The women who reported the best scores as it related to the family subscale and education were women who identified as having completed some college/technical courses. All of the women identified their friends as being supportive regardless of their education level.

The next question asked the participants about the area of employment (Figure 5).

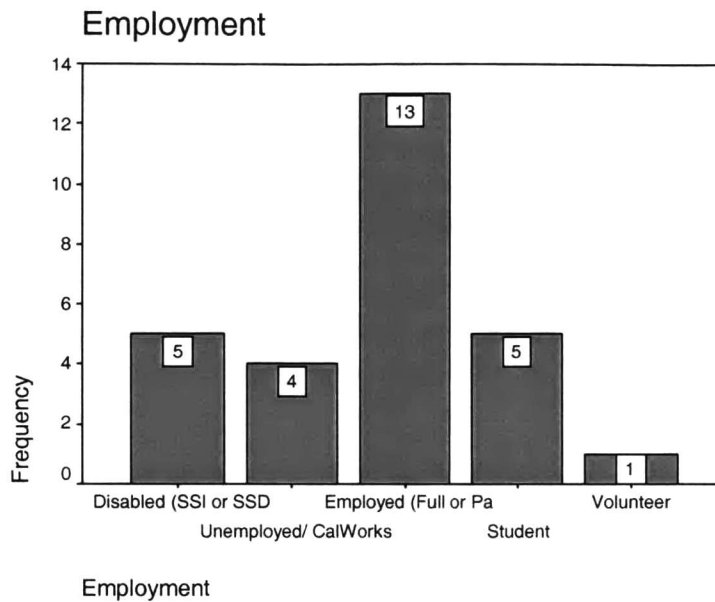


Figure 5-Employment-Frequencies (Bar Chart)

Participants were asked to select one category that best described her circumstance. The majority (13) of the women identified as being employed part-time or full-time. The employed women and women who were currently enrolled in school (5) felt that their family and friends supported them. Five of the participants identified as disabled and received some form of federal assistance (SSI or SSD). In reviewing the results of the family support, women who identified as being employed noted their family was supportive. One participant responded as a volunteer and felt that her family was not supportive at all. Women who were disabled felt that their friends were somewhat supportive while the rest of the participants felt that their friends provided a strong support system.

The next section of the survey requested the participants to respond to their health and quality of life.

### Analysis of Health and Quality of Life Scale

This section comprises findings on: (a) a woman's health today, (b) exercise, (c) doctor's appointment, rating of one's health 3 months ago which included: (d) walking, (e) eating, (f) bathing or dressing, (g) socializing with family/friends, and (h) keeping medical appointments.

The first question for this section requested the participants to rate their health as it pertained to the day that they completed the survey (Figure 6).

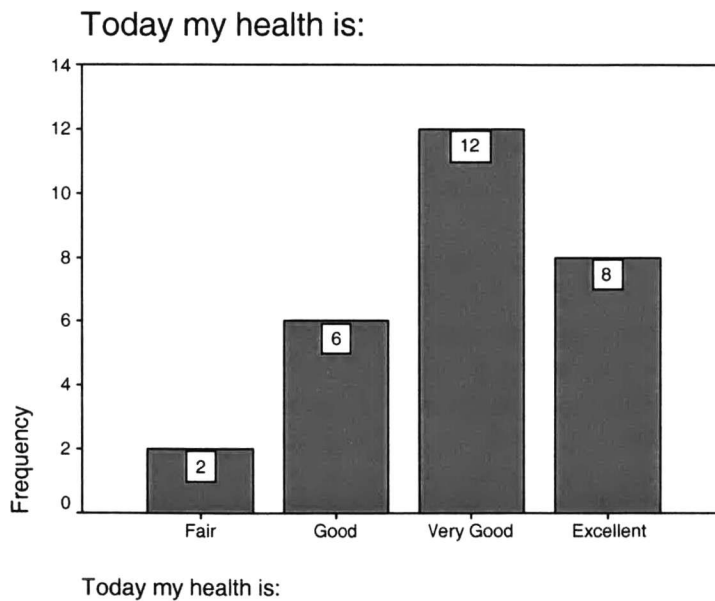


Figure 6. Rate of Health Today-Frequencies (Bar Chart)

Nothing tested statistically significant in this area. Eighteen of the participants responded that today their health was good/very good whereas only two of the

participants rated their health as fair/poor. Participants, who perceived their health as excellent, felt that their family was very supportive. All participants, regardless of their rating of their health today, felt that their friends were supportive.

The next question accessed a participant's ability to exercise (Figure 7).

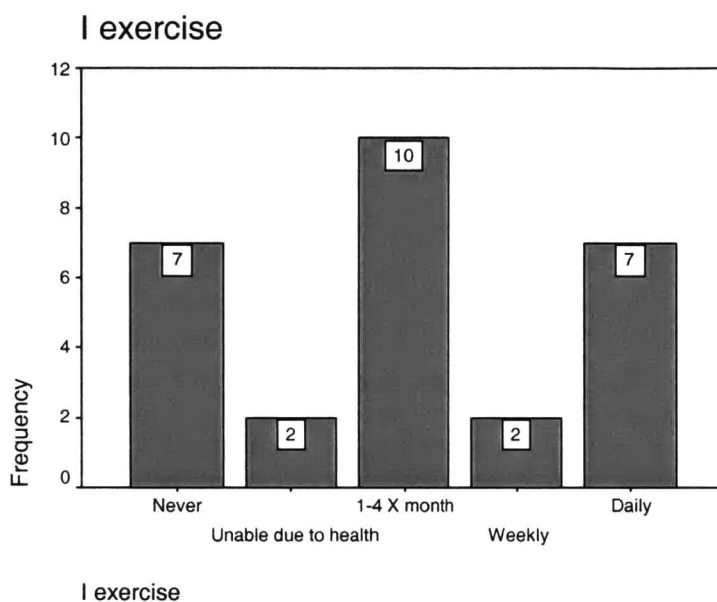


Figure 7. Exercise-Frequencies (Bar Chart)

The total scores tested significantly. Responses for this category showed that 10 of the respondents reportedly exercised 1-4 times a month. Seven of the women responded that they never exercised, with the same number replying that they exercise daily. Only 2 of the women answered that their health would not allow them to exercise. The family and friend score in this area showed trends with p-values of almost at .05. Women who exercised daily felt that their family supported them while women who did not participate in some form of daily exercise felt that their family provided very little

support.

In an effort to gather a better idea of how these women are taking an active part in their life, information regarding how often they attend their medical visit was needed (Figure 8).

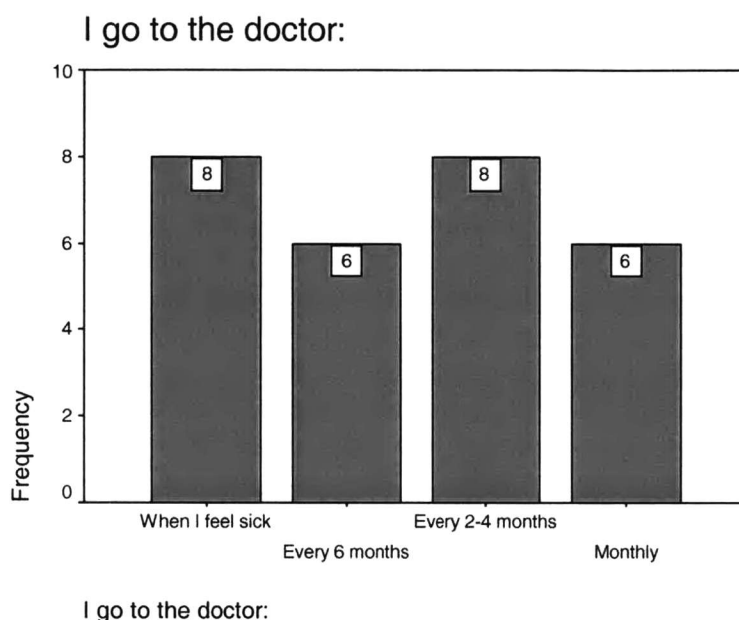


Figure 8. Doctor Visit-Frequencies (Bar Chart)

Eight participants responded that that they only went to their physician when they felt sick. Women who went to the doctor on a monthly basis, felt that their family and friends were supportive. Based on overall social support analysis scores, all of the women felt that their friends were supportive of them as it pertained to them taking care of their health.

The final 5 questions of the social support questionnaire required the participants to think about their health 3 months prior to completing this survey. The questions asked

the participants to rate themselves 3 months ago in their ability to walk, eat, bathe/dress, socialize with family/friends and lastly maintaining their scheduled medical appointments. For those questions, nothing tested statically significant. The participants responded that three months prior to completing the survey, 25 felt that they were able to walk with little or no assistance.

Twenty of the participants recalled that they had maintained an appetite and was able to eat with little to no assistance. In the areas of bathing and dressing, 24 of the participants recorded that they were able to perform this duty with little or no assistance. The area of socializing with family and friends responses showed no significant difference three months prior to the participant completing the survey. However the participants did rate that they socialized more and received more support from their friends during that time period then from their family

The last question for this section again focused on determining if the participant was taking an active part in maintaining a healthy health status. Twenty- two of the participants reported that their health ranged from good to excellent within that time period. Surprisingly, women who rated themselves as fair in keeping their medical appointments three months ago, felt that their friends were more supportive then their family.

### Summary

In reviewing the findings, it was noted that overall the women felt supported by their families and friends. In further analysis of the family status, the scores from the



same group of women suggested that they felt somewhat supported by their family and the strongest support from their friends. The study found that the all of the women had an established social support network and members of the network assisted as needed. The study also revealed that this sample of HIV-positive African-American women continued their lives after receiving their HIV/AIDS diagnosis.

Age, education level, employment, living situation and the length of time a woman knew of her diagnosis were insignificant as it pertained to the participant continuing to lead an active life. The support that these women received from family and friends directly influenced their lives. The positive influence that a woman received was demonstrated in the health and quality of life responses.

Overall most of the participants refused to allow their HIV/AIDS status to control their lives and independence. The responses indicated that each of the participants were able to complete their daily living activities on their own. The study also showed that majority of the women understood the need to keep their scheduled medical appointments that helped them maintain a healthy lifestyle. The HIV-positive African-American women in this study understood the importance of having a stable support system and the influence it has on one's quality of life.

## CHAPTER VI

### DISCUSSION AND IMPLICATION OF FINDINGS

The purpose of this study was to determine the relationship between social support and the quality of life for an HIV-positive African-American woman. Twenty-eight HIV-positive women from four HIV agencies in Oakland, California, voluntarily participated in the study. A brief social support questionnaire along with the Social Support Appraisal Scale was administered to the participants. The results of the study revealed that the participants felt supported by their families and friends but friends provided more support when needed.

There were consistencies that were noted between the literature review and this study. The first was the demographics of the HIV-positive African-American women who participated in the study were representative of samples of HIV-positive African-American women from larger studies. The common factors included that the women lived in an urban setting and though some were employed, they represented women who were from the lower socioeconomic level. Another common feature was that most of the women from the studies, like the participants, received their positive status while hospitalized with an opportunistic infection. Lastly, all of the women from all studies had a social support network that consisted of family (birth or constructed), friends and community that provided some type of support (informational, tangible or emotional).

There were two noticeable inconsistencies in a few of the reviewed studies and the participants of this study. The participants in this study reportedly utilized the medical services that were presented to them and majority of them continued their medical appointments as scheduled. Although this trend is highly unusual, especially for African Americans, a few of the reviewed studies indicated that once diagnosed women may delay receiving medical treatment for various reasons. The discrepancies could be due to the small size of this study's sample and that the participants in this study were integrated into a HIV/AIDS service agency.

#### Limitations of the Study

The small sample size was the greatest limitation of this study. Stigma, time, transportation, lack of childcare were factors that limited women participation in the study. The second limitation was the lack of incentives. Although efforts were made to collaborate with the agencies and the county HIV/AIDS department to secure incentives (ten minutes telephone cards), the cards were not available during the study.

The questions that were posed were also limited. The questionnaires lacked probing question that would have established more of a relationship between social support and quality of life. Additional questions that should have been included were:

- Number of children?
- Are your children living with you, family/relatives or are they in the foster care system?
- What form of transmission best describes the way you contracted the disease?
- If involved in a relationship, is your partner aware of your health status?

- Are you practicing safe sex **everytime** you engage in sexual acts?
- Are you aware of your partner's HIV/AIDS status?
- Are you currently or in the past, engaged in obsessive drug or alcohol use?
- In addition to your physician, are you currently utilizing the services of non-traditional practitioners to enhance your health?

The inclusion of these questions would have allowed further exploration into the areas of social support not only from family members and friends, but also the participant's informal and formal support systems.

Based on the findings of this study it has determined that the more established a woman's support network is prior to her being diagnosed, the more likely she will be able to receive support once she receives a positive diagnosis. An established support network provides a woman with an understanding of the roles and responsibilities of the people who comprise her network. She should expect her network to expand and contract according to the quality of her health.

A woman's social support network influences her quality of life. Her informal and formal support systems affect her health as well as her everyday activities. Physicians, pharmacists, nurses, case managers, social workers, lawyers and advocates are all parts of a woman's formal support system and each has its individual roles in her support system. Family and friends are parts of her informal support system and their influence can cause a shift in a woman's support system. Ultimately, it is the HIV-positive woman's decision on how active a part she will take in living with the disease and how she will incorporate her social support system (informal and formal) into maintaining her quality of life.

### Implication for Social Work Practice

There are five points from this study that can be used to enhance social work practice. The first of these is awareness. Over the past five there has been a decrease in HIV/AIDS awareness campaigns that specifically target the African-American community. The health and human services HIV/AIDS campaigns that once targeted African Americans have been replaced with other health disparities (asthma, breast cancer, hypertension, diabetes and heart disease) that are prevalent in the African-American community. This is not to say that information about these and other health disparities are not valid, but there is a need to keep HIV and AIDS in the public eyes of the African-American community. The marketing images of a HIV-positive person have caused a false sense of what it means to live with HIV. Advertisements images depict a health, smiling and youth male or female or in the case of Ervin “Magic” Johnson, a healthy athlete. There were not the images that were published and distributed at the peak of the AIDS epidemic.

Images at the height of the pandemic represented Caucasian males who were dying at an alarming rate. Graphic images of emaciated males who resembled Nazi concentration camp victims were posted throughout the gay, white male community. The result forced the white gay community to become aware of the devastation of the disease and to create education/prevention awareness programs that specifically targeted the gay, white male community. As HIV medications began to prolong the lives of people living with the disease, the pharmaceutical companies that manufactured the medicines replaced the “shock” images with pleasing-to-the-eye images. This false picture of living with

HIV or AIDS has not reduced the number of African Americans who continue to become infected.

Reduction in the number of African Americans, particularly women who become infected, is the second point of this study. African-American women continue to contract HIV at an alarming rate, especially women in the age group of 18-44. Programs that are African-American targeted should focus on the educational and economical needs of the community. Women in particular should understand the importance of being able to sustain and maintain her identity in her relationships. She should understand that she is the person who controls her destiny. Empowerment begins with education and knowledge. In addition, series that examine healthy relationships, safe sex, communication, substance abuse and health are needed to educate the African-American community about ways to reduce the rate of HIV/AIDS and increase the understanding of the affects HIV/AIDS has in the community.

The third point is the need for more involvement from the African-American community. Health clinics, hospitals, school and clinics should design prevention and education information that are gender-specific as well as age-specific for African-Americans. The information should be available not only in the traditional agencies but any place that people gather. Barbershops, hair and nail salons, car washes/detail shops, daycares, restaurants and bars are just a few of the places that African Americans frequent on a regular basis. The constant bombardment of prevention messages along with easy to read pamphlets would serve as a constant reminder that HIV/AIDS is still occurring.

Outreach within the community by HIV service providers would assist in executing services that target the various sub-groups (gay, bisexual, transgender, 55 and over age group, sex workers, substance abusers) within the African-American community. The services within the community would be designed to not only reduce the stigma associated with the individual's lifestyle but to provide a safe place to ask questions. Outreach workers should represent the people in the community and be comfortable informing the community about the importance of wearing protection when engaging in sexual practices, domestic violence, substance abuse, homosexuality and ageism. Outreach workers should also be able to conduct on-site HIV testing and distribute safe sex kits. Outreach to teens (13-17) should also occur with the consent of the parent/guardian. Peer educators should provide basic general information surrounding health, healthy relationships, teen dating violence and knowing one's body. Information would be available to parents on how to talk to their youth about HIV/AIDS in the African-American community.

Point four of this study centers around support. A woman who learns of her diagnosis must increase her formal support system and utilize their services. Formal informational resources (medical social workers) are needed to assist with educating a woman on HIV and the progression of the disease. Medical providers can assist the woman in maintaining an active lifestyle while monitoring other health issues that may occur. An informal support group may provide a woman with emotional and informational support.

Family and friends that comprise a woman's informal support group may have questions and need emotional support themselves. There should be a place in the

community where their questions can be answered. This place should also offer training and education around HIV and other health disparities in the African-American community. The training would offer information to not only a woman's partner but to her family and the community in large. The training would be two-fold. First it would educate the community about HIV/AIDS. This would hopefully lead to a reduction of African-Americans in that community who would become infected. Secondly, it would raise awareness. The raise of awareness would hopefully bring the community together to challenge the leaders of the community to address HIV and other issues that surround it (homelessness, substance abuse, unemployment, underinsured/uninsured, high education dropout rate, high crime rate). To address the aforementioned issues, funding would need to be available.

Funding, the fifth and final implication for social work, for HIV/AIDS programs have been drastically cut over the past five years (Wagner, 1997). This occurred when the Center for Disease Control declared HIV as a chronic disease (more people were living) and the number of individuals dying from the disease had decreased. The report failed to mention that this number was based on the white gay male community and did not include communities of color or women. The funding cut has caused community-based organizations and agencies to reduce their staff and some have eventually been forced to close. The economy has forced philanthropists and other private donors to decrease their monetary gifts. The federal government has decreased funding for HIV research and services. The African-American community and other communities of color



have to unite and advocate for HIV funding and remind local elected officials that AIDS is still one of the top five related causes of death in communities of color.

Social workers should stay abreast of what is occurring in the community and political arena. They should be able to provide the support (informational and sometimes emotional) necessary to empower clients and the community to advocate for themselves and for others who are unable due to health or fear of being stigmatized. The five points are attainable but social workers have to be able to stand with clients, families and communities in front of the political leaders and remind them that HIV and AIDS is still destroying the African-American community.

## APPENDICES

## Appendix A

### The Effects of Social Support Consent Form

You are invited to participate in a study of HIV-positive African-American women. The purpose of the study is to understand the correlation between the woman and her social support network that she has established. The study seeks to identify which area(s) of social support (tangible, emotional or informational) is most useful to the HIV-positive woman. The information will assist me in the writing of my thesis as well as to better understand how some HIV-positive women utilize their social support network to manage their health as well as to maintain their quality of life.

**Questionnaire.** The questionnaire is brief and should take 10-15 minutes. Please carefully read and circle the answer that best applies to you. You may refuse to answer any question. To ensure the confidentiality of your responses, your name will not be required on any part of the questionnaire. Your first initial, last name will only appear on the consent form, that you will separate from the questionnaire and place in the accompanying envelope. Although there are no names on the questionnaires, the information for the study will be kept confidential. **All data will be securely stored and destroyed after the study.**

Your participation in this study is strictly voluntary. The information that will come from this study will assist in future studies focusing on HIV-positive African-American women who have established good support network. This study should also identify how the different social support systems interlock and are used to maintain balance in a woman's bio-psychosocial environment.

If you have questions or concerns regarding this research project, you may contact the researcher, Johnetta Myers at (510) 448-4181.

Your signature below indicates that you have read and understand the procedures of this study and that you agree to participate in this study. Thank you for your consent to participate in this study. Upon completion, please place questionnaire in the envelope, seal envelope and place envelope in box titled **"Social Support"**.

Print Name (1<sup>st</sup> initial, last name) \_\_\_\_\_

Please select the site that referred you and put that number in the box:

1=Highland Hospital

2=AMHI

3=APEB

4=WORLD

☐

## Appendix B

## AGENCY PARTICIPATION LETTER

You are invited to participate in a study of women infected and affected with HIV in Alameda County. The purpose of the study is to understand the correlation between the woman, her social support network and her quality of life. The study seeks to identify which area(s) of social support (tangible, emotional or informational) is most useful to the HIV-positive woman. The information will assist me in the writing of my thesis as well as to better understand how HIV-positive women utilize their social support network to manage their health as well as to improve their quality of life.

Your participation in this study is strictly voluntary and appreciated. This study is designed to assess the needs of HIV positive women in Alameda County, the impact of HIV on the family, identify the benefits of gender-specific services, and the ultimate goal is to improve the quality of life of HIV positive women residing in Alameda County. The request for your agency's involvement stems from exploring the benefits of utilizing comprehensive health and social services approaches to addressing needs of HIV positive women.

The survey is brief and should take approximately 10-15 minutes to complete. Please review the sample survey and offer any suggestions that may deem it more appropriate for your clients. **The survey information collected will not include any of the participants' identifying characteristics such as names, addresses, social security numbers or telephone numbers. The completed surveys will be destroyed after the data is analyzed.**

If you have questions or concerns regarding this research project, you may contact the researcher, **Johnetta Myers Clark Atlanta University MSW Graduate Student at 510-593-9848 (cell phone) or 510-448-4181 (pager).**

Thank you in advance for your agency's consent to participate in this study.

Name of Agency: \_\_\_\_\_

Executive Director (print name): \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Researcher: Johnetta Myers

## Appendix C

## SOCIAL SUPPORT QUESTIONNAIRE

## Demographic Information

|                  |                          |                          |                                    |                          |                    |
|------------------|--------------------------|--------------------------|------------------------------------|--------------------------|--------------------|
| Age Group        | <b>1</b><br>18-23        | <b>2</b><br>24-29        | <b>3</b><br>30-35                  | <b>4</b><br>36-41        | <b>5</b><br>42-44  |
| Marital Status   | Single/<br>never married | Married                  | Living w/<br>partner               | Separated/<br>divorced   | Widowed            |
| Living Situation | Lives Alone              | Lives w/<br>roommate     | Lives w/<br>spouse/partner         | Lives w/<br>family       | Other              |
| Education        | Some high<br>school      | High school<br>graduate  | Some college/<br>technical courses | College/tech<br>graduate | Graduate<br>school |
| Employment       | Disabled<br>(SSI or SSD) | Unemployed/<br>Cal-works | Employed<br>Part or Full time      | Student                  | Volunteer          |

Year Diagnosed with HIV/AIDS \_\_\_\_\_

## Health and Quality of Life Information

|                                       |           |           |                   |                      |                  |
|---------------------------------------|-----------|-----------|-------------------|----------------------|------------------|
| <b>Today my health is:</b>            | Excellent | Very Good | Good              | Fair                 | Poor             |
| I exercise                            | Daily     | Weekly    | 1-4 times a month | Unable due to health | Never            |
| I go to the doctor                    | Weekly    | Monthly   | Every 2-4 months  | Every 6 months       | When I feel sick |
| Rate your health <b>3 months</b> ago: |           |           |                   |                      |                  |
| Walking                               | Excellent | Very Good | Good              | Fair                 | Poor             |
| Eating                                | Excellent | Very Good | Good              | Fair                 | Poor             |
| Bathing<br>Or Dressing                | Excellent | Very Good | Good              | Fair                 | Poor             |
| Socializing with<br>Family/friends    | Excellent | Very Good | Good              | Fair                 | Poor             |
| Keeping Medical<br>Appointments       | Excellent | Very Good | Good              | Fair                 | Poor             |

## Appendix D

## Social Support Appraisal Scale (SSA)

Below is a list of statements about your relationships with family and friends. Please indicate how much you agree or disagree with each statement as being true.

(Circle one number in each row)

|   | Strongly<br>agree | Agree | Dis-<br>agree | Strongly<br>disagree |
|---|-------------------|-------|---------------|----------------------|
| 1. My friends respect me.                   | 1                 | 2     | 3             | 4                    |
| 2. My family cares for me very much.        | 1                 | 2     | 3             | 4                    |
| 3. I am not important to others.            | 1                 | 2     | 3             | 4                    |
| 4. My family holds me in high esteem.       | 1                 | 2     | 3             | 4                    |
| 5. I am well liked.                         | 1                 | 2     | 3             | 4                    |
| 6. I can rely on my friends.                | 1                 | 2     | 3             | 4                    |
| 7. I am really admired by my family.        | 1                 | 2     | 3             | 4                    |
| 8. I am respected by other people.          | 1                 | 2     | 3             | 4                    |
| 9. I am loved dearly by my family.          | 1                 | 2     | 3             | 4                    |
| 10. My friends don't care about my welfare. | 1                 | 2     | 3             | 4                    |
| 11. Members of my family rely on me.        | 1                 | 2     | 3             | 4                    |
| 12. I am held in high esteem.               | 1                 | 2     | 3             | 4                    |
| 13. I can't rely on my family for support.  | 1                 | 2     | 3             | 4                    |
| 14. People admire me.                       | 1                 | 2     | 3             | 4                    |
| 15. I feel a strong bond with my friends.   | 1                 | 2     | 3             | 4                    |
| 16. My friends look out for me.             | 1                 | 2     | 3             | 4                    |
| 17. I feel valued by other people.          | 1                 | 2     | 3             | 4                    |
| 18. My family really respects me.           | 1                 | 2     | 3             | 4                    |

## Appendix D (continued)

## Social Support Appraisal Scale (SSA)

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(Circle one number in each row)

|  | Strongly<br>agree<br>1 | Agree<br>2 | Dis-<br>agree<br>3 | Strongly<br>disagree<br>4 |
|--|------------------------|------------|--------------------|---------------------------|
| 19. My friends and I are really important to each other. |                        |            |                    |                           |
| 20. I feel like I belong.                                | 1                      | 2          | 3                  | 4                         |
| 21. If I died tomorrow, very few people would miss me.   | 1                      | 2          | 3                  | 4                         |
| 22. I don't feel close to members of my family.          | 1                      | 2          | 3                  | 4                         |
| 23. My friends and I have done a lot for one another.    | 1                      | 2          | 3                  | 4                         |

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